

GENERAL ASSEMBLY OF NORTH CAROLINA
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SENATE BILL DRS15394-NIa-190D

Short Title: Omnibus Life Sciences Appropriations. (Public)

Sponsors: Senators Sawrey and Chaudhuri (Primary Sponsors).

Referred to:

1 A BILL TO BE ENTITLED
2 AN ACT APPROPRIATING FUNDS TO THE DEPARTMENT OF COMMERCE FOR
3 VARIOUS PURPOSES; REVISING THE COMPOSITION AND DUTIES OF THE
4 ADVISORY COUNCIL ON RARE DISEASES; TRANSFERRING THE COUNCIL TO
5 THE DEPARTMENT OF HEALTH AND HUMAN SERVICES; APPROPRIATING
6 FUNDS TO THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO COVER
7 THE OPERATING EXPENSES OF THE COUNCIL; ALLOWING CERTAIN WATER
8 AND SEWER ECONOMIC DEVELOPMENT PROJECTS; AND CREATING THE LIFE
9 SCIENCE AND BIOMANUFACTURING TECHNOLOGIES RESERVE FUND.

10 The General Assembly of North Carolina enacts:

11
12 **PART I. ONE NORTH CAROLINA SMALL BUSINESS ACCOUNT APPROPRIATION**

13 **SECTION 1.** There is appropriated from the General Fund to the Department of
14 Commerce the sum of ten million dollars (\$10,000,000) in recurring funds beginning in the
15 2026-2027 fiscal year to be allocated to the One North Carolina Small Business Account
16 established in G.S. 143B-437.71.

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18 **PART II. NORTH CAROLINA BIOTECHNOLOGY CENTER APPROPRIATION**

19 **SECTION 2.** There is appropriated from the General Fund to the Department of
20 Commerce for the North Carolina Biotechnology Center (the Center) the sum of two million
21 dollars (\$2,000,000) in recurring funds beginning in the 2026-2027 fiscal year to support life
22 science company funding, university technology development, workforce development, and
23 economic development programs administered by the Center.

24
25 **PART III. ADVISORY COUNCIL ON RARE DISEASES**

26 **SECTION 3.1.** Part 6 of Article 1B of Chapter 130A of the General Statutes reads
27 as rewritten:

28 "Part 6. Taylor's Law Establishing the Advisory Council on Rare Diseases.

29 "**§ 130A-33.65. Advisory Council on Rare Diseases; membership; terms; compensation;
30 meetings; quorum.**

31 (a) Short Title. – This Part shall be known as Taylor's Law Establishing the Advisory
32 Council on Rare Diseases.

33 (a1) Establishment of Advisory Council. – There is established the Advisory Council on
34 Rare Diseases within the ~~School of Medicine of the University of North Carolina at Chapel Hill~~
35 Department of Health and Human Services to advise the Governor, the Secretary, and the General
36 Assembly on research, diagnosis, treatment, and education relating to rare diseases. ~~This Part~~



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1 shall be known as Taylor's Law Establishing the Advisory Council on Rare Diseases. For
2 purposes of this Part, "rare disease" has the same meaning as provided in 21 U.S.C. § 360bb.

3 (b) Advisory Council Membership. – The advisory council shall consist of 19 members
4 to be appointed as follows:

5 (1) ~~Upon the recommendation of the Dean of the School of Medicine of the~~
6 ~~University of North Carolina at Chapel Hill, the~~ The Secretary shall appoint
7 ~~members to the advisory council as follows:~~the following 15 members:

8 a. ~~A physician~~ Two physicians licensed and practicing in this State with
9 experience researching, diagnosing, or treating rare diseases.

10 b. ~~A medical researcher with experience conducting research concerning~~
11 ~~rare diseases.~~

12 c. ~~A~~ One registered nurse or advanced practice registered nurse licensed
13 and practicing in the State with experience treating rare diseases.

14 d. ~~One rare diseases survivor.~~

15 e. ~~One member who represents a rare diseases foundation.~~

16 f. ~~One representative researcher from each~~ an academic research
17 institution in this State that receives any grant funding for rare diseases
18 research.

19 g. ~~One parent of a childhood rare disease survivor.~~

20 h. One hospital administrator, or the hospital administrator's designee,
21 representing a hospital in the State that provides care to persons
22 diagnosed with a rare disease.

23 i. Two persons age 18 or older who have been diagnosed with a rare
24 disease.

25 j. Two persons age 18 or older who are, or were previously, caregivers
26 to a person diagnosed with a rare disease.

27 k. One representative of a rare disease patient organization that operates
28 in the State.

29 l. One pharmacist licensed and practicing in this State with knowledge
30 and experience regarding drugs used to treat rare diseases.

31 m. One representative of the life sciences, biotechnology, or
32 biopharmaceutical industry that either focuses on research efforts
33 related to the development of therapeutic products for persons
34 diagnosed with a rare disease or has demonstratable understanding of
35 the path to commercialization of such products.

36 n. Two representatives of a health benefit plan or health insurer, at least
37 one of whom is a representative of a North Carolina Medicaid
38 Managed Care health plan.

39 o. One genetic counselor with experience providing services to persons
40 diagnosed with a rare disease or caregivers of persons diagnosed with
41 a rare disease.

42 (2) ~~The chairs of the Joint Legislative Oversight Committee on Health and Human~~
43 ~~Services, or the chairs' designees, shall serve on the advisory council. A~~
44 ~~member of the advisory council who is designated by the chairs of the Joint~~
45 ~~Legislative Oversight Committee on Health and Human Services may be a~~
46 ~~member of the General Assembly.~~

47 (2a) One member appointed by the President Pro Tempore of the Senate.

48 (2b) One member appointed by the Speaker of the House of Representatives.

49 (2c) One member appointed by the Governor.

50 (3) The Secretary, or the Secretary's designee, shall serve as an ex officio,
51 nonvoting member of the advisory council.

1 (c) ~~Members~~ Length of Terms. – All initial members appointed pursuant to subsection
2 ~~(b) of this section to the advisory council~~ shall serve for a term of three years, and no member
3 initial member, except for the initial physician members and the initial member representing a
4 rare disease patient organization, shall serve more than three consecutive terms. The initial
5 physician members and the initial member representing a rare disease patient organization may
6 serve for up to four consecutive terms. Thereafter, members appointed by the President Pro
7 Tempore of the Senate, the Speaker of the House of Representatives, and the Governor shall
8 serve for a term of two years; and members appointed by the Secretary shall serve for a term of
9 two, three, or four years, as determined by the chair of the advisory council.

10 (c1) Vacancies and Removals. – Any appointment to fill a vacancy on the advisory council
11 created by the resignation, dismissal, death, or disability of a member shall be filled by the
12 appointing authority for the balance of the unexpired term. Each appointing authority may
13 remove any member appointed by that appointing authority for misfeasance, malfeasance, or
14 nonfeasance.

15 (d) Per Diem and Expenses. – Members of the advisory council shall receive per diem
16 and necessary travel and subsistence expenses in accordance with the provisions of G.S. 138-5
17 or G.S. 138-6 or travel and subsistence expenses in accordance with the provisions of
18 G.S. 120-3.1, as applicable.

19 (e) Administrative Support. – All administrative support and other services required by
20 the advisory council shall be provided by the ~~School of Medicine of the University of North~~
21 ~~Carolina at Chapel Hill Department.~~

22 (f) ~~Upon the recommendation of the Dean of the School of Medicine of the University~~
23 ~~of North Carolina at Chapel Hill, Selection of Chair.~~ – The Secretary shall select the chair of the
24 advisory council from among the members of the council. The chair shall serve in this position
25 until the expiration of his or her term.

26 (g) ~~The chair shall convene the first meeting of the advisory council no later than October~~
27 ~~1, 2015.~~ Meetings and Quorum. – A majority of the council members shall constitute a quorum.
28 A majority vote of a quorum shall be required for any official action of the advisory council.
29 Following the first meeting, the advisory council shall meet at least quarterly. The advisory
30 council may meet more frequently upon the call of the chair or upon the request of a majority of
31 council members.

32 **"§ 130A-33.66. Advisory Council on Rare Diseases; powers and duties; reports.**

33 The advisory council shall have the following powers and duties:

- 34 (1) ~~Advise on coordinating the Governor, the Secretary, and the General~~
35 Assembly on all of the following:
- 36 a. Coordination of statewide efforts for the to study of the incidence of
37 rare diseases within the State and the status of the rare disease
38 community.
 - 39 b. Coordination of statewide efforts to increase public awareness and
40 understanding of rare diseases.
 - 41 c. Identification of policy issues related to rare diseases and the
42 advancement of policy initiatives related to rare diseases at the State
43 and federal levels.
 - 44 d. The appropriation of State funds to facilitate increased public
45 awareness of and improved treatment for rare diseases.
- 46 (2) Report to the Secretary, the Governor, ~~and the Joint Legislative Oversight~~
47 Committee on Health and Human Services ~~Services~~, and the Fiscal Research
48 Division on behalf of the General Assembly not later than January 1, 2016,
49 and annually thereafter, on the activities of the advisory council and its
50 findings and recommendations regarding rare disease research and care in
51 North Carolina, including any recommendations for statutory changes and

1 amendments to the structure, organization, and powers or duties of the
2 advisory council.

3 (3) In consultation with accredited medical schools, accredited schools of public
4 health, and hospitals licensed to operate in the State that provide care to
5 persons diagnosed with a rare disease, develop resources or recommendations
6 regarding quality of and access to treatment and services available within the
7 State for persons diagnosed with a rare disease.

8 (4) Advise and consult with the Department, the North Carolina Drug Utilization
9 Review Board, and the Medicaid Preferred Drug List Review Panel in
10 developing recommendations, resources, and programs relating to the
11 diagnosis and treatment of rare diseases.

12 (5) Identify additional relevant areas for the advisory council to study and
13 evaluate."

14 **SECTION 3.2.** There is appropriated from the General Fund to the Department of
15 Health and Human Services the sum of two hundred fifty thousand dollars (\$250,000) in
16 recurring funds beginning in the 2026-2027 fiscal year to be allocated to cover the operating
17 expenses of the Advisory Council on Rare Diseases authorized by G.S. 130A-33.65, as amended
18 by Section 3.1 of this act.

19 20 **PART IV. WATER AND SEWER ECONOMIC DEVELOPMENT PROGRAM**

21 **SECTION 4.(a)** Award Authorized. – Pursuant to Part 2H of Article 10 of Chapter
22 143B of the General Statutes, the Department of Commerce may commit in a Governor's Letter
23 to reimburse, over a period of time not less than 10 years, a business, as defined in
24 G.S. 143B-437.51, for the costs incurred for an eligible project. For purposes of this section, an
25 eligible project is the construction of, or improvements to, new or existing water or sewer lines,
26 facilities, or equipment for new, proposed, or existing buildings by the business, and can include
27 water reuse and water reclamation projects, if the business commits, in a company performance
28 agreement, to the requirements of subsection (c) of this section.

29 **SECTION 4.(b)** Award Amount. – The total amount that may be committed for
30 reimbursement under this section is equal to the lesser of (i) fifty million dollars (\$50,000,000)
31 or (ii) fifty percent (50%) of the cost of the eligible project. The maximum amount that can be
32 paid out in a single calendar year for all but the final year of the award term is the lesser of
33 one-tenth of the amount committed or one-half of the costs incurred and verified by the business
34 for that calendar year.

35 **SECTION 4.(c)** Company Performance Agreement. – For a project to be eligible
36 under this section, a business must commit to the following requirements in addition to those
37 contained in G.S. 143B-437.72(b):

38 (1) Invest at least two billion dollars (\$2,000,000,000) of private funds in the
39 development or expansion of the manufacturing site served by or located
40 within the same county as the eligible project.

41 (2) For the greater of the term of the agreement or 10 years, create at least 500
42 new jobs having an overall average compensation that exceeds the average
43 wage for all insured private employers in the county in which the eligible
44 project is located and maintain both the new and existing jobs of the business
45 in that county.

46 (3) Annually verify costs incurred for the eligible project.

47 (4) Ensure that the eligible project will supply at least sixty percent (60%) of the
48 total aggregate water and wastewater needs required by the manufacturing site
49 as developed or expanded by the investment made under subdivision (1) of
50 this subsection.

- 1 (5) Not seek or accept any other grant from the State, including a grant pursuant
2 to Part 2G of Article 10 of Chapter 143B of the General Statutes, for any jobs
3 created as part of the company performance agreement.

4 **SECTION 4.(d)** One NC Commitment Exclusion. – The amount committed pursuant
5 to this section shall not be included in calculating the amount authorized to be committed
6 pursuant to G.S. 143B-437.71(b1).

7 **SECTION 4.(e)** Agreement Binding. – A Governor's Letter issued pursuant to this
8 section is a binding obligation of the State and is not subject to State funds being appropriated
9 by the General Assembly.

10 **SECTION 4.(f)** Match Requirement. – Notwithstanding G.S. 143B-437.72(c)(1), a
11 local government is not required to match the funds allocated by the State for an eligible project
12 under this section.

13 14 **PART V. LIFE SCIENCE AND BIOMANUFACTURING TECHNOLOGIES RESERVE** 15 **FUND**

16 **SECTION 5.(a)** Initial Capitalization Transfer. – There is transferred from the
17 General Fund to the Life Science and Biomanufacturing Technologies Reserve Fund established
18 in subsection (b) of this section the sum of twenty million dollars (\$20,000,000) in nonrecurring
19 funds for the 2026-2027 fiscal year.

20 **SECTION 5.(b)** Fund Established; Purpose. – There is created the Life Science and
21 Biomanufacturing Technologies Reserve Fund (the Reserve) to be administered by the Office of
22 State Budget and Management. Funds in the Reserve shall be available only for appropriation by
23 the General Assembly and shall be used to provide State matching funds, cost-share
24 contributions, and other financial support for joint federal, State, local government, and industry
25 initiatives involving emerging life science or biomanufacturing technologies.

26 **SECTION 5.(c)** Eligible Uses. – Eligible uses of funds from the Reserve include:

- 27 (1) State matching funds for federal grants or cooperative agreements related to
28 life science research, development, or manufacturing.
29 (2) Cost-share contributions required for competitive federal programs, including
30 programs administered by the National Institutes of Health, the Biomedical
31 Advanced Research and Development Authority (BARDA), the Advanced
32 Research Projects Agency for Health (ARPA-H), or the Department of
33 Commerce Economic Development Administration.
34 (3) Financial for public-private partnerships involving life science or
35 biomanufacturing facility development, workforce development, or
36 technology transfer initiatives.
37 (4) Seed funding for multigovernmental consortia or regional innovation hubs
38 focused on biomanufacturing technologies, cell and gene therapy
39 manufacturing, advanced pharmaceutical manufacturing, or related fields.

40 **SECTION 5.(d)** Appropriation Required. – Funds in the Reserve shall not be
41 expended except upon an act of appropriation by the General Assembly designating the specific
42 initiative, purpose, and amount to be disbursed from the Reserve.

43 **SECTION 5.(e)** Reporting. – The Director of the Budget shall report to the Joint
44 Legislative Economic Development and Global Engagement Oversight Committee and the Fiscal
45 Research Division no later than March 1 of each fiscal year that funds are appropriated from the
46 Reserve. The report required under this subsection shall include, at a minimum, the balance of
47 the Reserve, any proposals received for use of Reserve funds, and recommendations regarding
48 capitalization of the Reserve for the ensuing biennium.

49 50 **PART VI. EFFECTIVE DATE**

1 **SECTION 6.** Parts 1, 2, 3, and 5 of this act become effective July 1, 2026. Except as
2 otherwise provided, the remainder of this act is effective when it becomes law.